ASSOCIATION OF PERCEIVED STIGMA WITH GLYCEMIC CONTROL IN YOUTH AND YOUNG ADULTS WITH TYPE 1 DIABETES IN RWANDA

by

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ABSTRACT

Background: Research suggests that stigma may affect the management of glycemic control in people with diabetes. The aim of this study was to evaluate perceived stigma among youth and young adults with type 1 diabetes (T1D) who are current or past recipients of care from the Life for a Child (LFAC) program. We hypothesized that perceived stigma differs by glycemic control, age, duration of type 1 diabetes, sex, and vocational center attendance.

Methods: Hospitals with pools of former vocational center attendees were targeted for participant recruitment. Research staff administered a 25–item adapted version of the Berger HIV Stigma Scale. Higher scores indicate more stigma. Scores were summarized using median (IQR). The association between perceived stigma and glucose control were assessed by both Spearman's correlation coefficient and a Wilcoxon rank sum test. Perceived stigma scores were compared according to age and duration of diabetes, using Spearman's correlation coefficient,

and according to groups defined by sex and vocational center attendance using Wilcoxon rank sum tests.

Results: All 54 (24 current, 30 former) approached LFAC participants completed the questionnaire. Ages ranged from 15-32 years; 31(57%) female. Stigma scores ranged from 48-83(median=64,IQR:55-67) and were weakly correlated with HbA1c(r_s=0.31,p=0.11). Those with adequate glycemic control did not differ in terms of perceived stigma from those with poor glycemic control (p=0.25). Perceived stigma did not correlate significantly with age(r_s=-0.21,p=0.14) or duration of diabetes(r_s=-0.23,p=0.1). However, median scores were lower in males (56, IQR=53-66) than females(66,IQR=58-69; p=0.01). Median scores were higher in former center attendees than non-attendees(66, IQR=62-69 and 54, IQR=52-62, respectively)(p< 0.01).

Conclusion: Previous research employed qualitative methods to capture stigma in patients with T1D. Ours, we believe, is the first to examine perceived stigma of T1D quantitatively. Our results show that perceived stigma only weakly correlates with glycemic control, but they also confirm the hypothesis that females perceive a greater amount of stigma than males. However, our adapted stigma scale is not validated for this population.

Public health significance: Our findings of differences in perceived stigma by sex and vocational center attendance should help inform future interventions to improve psychological well being and self-management of T1D.

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1.0 Introduction

Diabetes is a chronic illness that presents when there is insufficient insulin being produced by the pancreas, either through the destruction of beta cells (Type 1) or when the body is resistant to insulin and there is insufficient insulin secretion to overcome this resistance (Type 2) (Global Reports on Diabetes, 2016). In 2014-2015, it was estimated that 415-422 million adults worldwide were living with diabetes (Global Reports on Diabetes, 2016, Diabetes: Facts and Figures, 2015). The age-standardized global prevalence of diabetes in adults has increased from 4.7% in 1980 to 8.5% in 2014 (Global Reports on Diabetes, 2016). This increase may, in part, be attributed to the increase in obesity over the past decade, which is a risk factor for type 2 diabetes. Additionally, urbanization, increasingly sedentary lifestyles, nutrition, and aging populations may also be contributing to this increase (Global Reports on Diabetes, 2016, IDF Diabetes Atlas, 2015, Hu, 2011).

Currently, diabetes is on the rise in both low-income and middle-income countries (Global Reports on Diabetes, 2016, Diabetes: Facts and Figures, 2015, Dagenais et al., 2016), with three-fourths of people with existing diabetes worldwide living in these countries, as compared to high-income countries (Diabetes: Facts and Figures, 2015). In 2015, 10.5% of the United States population, ages 20-79, had diabetes, while the same age group in low and middle-income countries such as Guatemala, Jordan, Turkey, and Malaysia had diabetes rates of 11.1%, 11.7%, 12.8% and 17.9% respectively (Diabetes Prevalence, 2016). In order to accurately distinguish between type 1 and type 2 diabetes, laboratory tests may be needed. Therefore, global estimates by diabetes type are difficult to obtain (Global Reports on Diabetes,

2016). However, it is estimated that 5-10% of all diabetes cases are type 1 (Diabetes, Zimmet et al., 2001).

The International Diabetes Federation (IDF) has estimated that the incidence of type 1 diabetes is increasing by 3% each year worldwide (Onkamo et al., 1999, Type 1 Diabetes, 2011). However, very little is known about the cause of this increase in incidence (Type 1 Diabetes, 2011, Gale, 2002). Since these changes have been observed in stable populations, it is possible that changes in the environment and factors related to socioeconomic status may be linked to this increase (Type 1 Diabetes, 2011, Gale 2002, Egro, 2013). Other hypotheses proposed to explain the observed increase in diabetes incidence include the potential protective factor of early childhood exposure to certain infectious agents such as tuberculosis, mumps, measles, enterovirus, hepatitis A, rubella, rotavirus, and cytomegalovirus (Ergo, 2013, Tracy et al., 2010, Bach, 2002, Kolb & Elliott, 1994), vitamin D deficiency potentially impacting diabetes development, and insufficient breastfeeding of children with a genetic susceptibility to diabetes (Kimpimaki et al., 2001, Mooney et al., 2004, Sloka et al., 2010). Due to this evidence found in human and animal models, it is unlikely that this increase is due to a single factor (Egro, 2013).

In 2014, the period prevalence of diagnosed type 1 diabetes from seven districts within Rwanda for those aged less than 26 was 16.4 per 100,000 and 4.8 per 100,000 for those younger than 15 years of age (Marshall et al., 2015b). This increase in prevalence with age is consistent with previous research (Maahs, 2010, Swai et al., 1993, Khalifa et al., 1997). Overall, females under the age of 26 had a higher prevalence of diabetes with 18.5 cases per 100,000 compared to 14.1 cases per 100,000 in males (Marshall et al., 2015b). This trend has also been seen in Libya (Kadiki & Roaeid, 2002); however, in other parts of the world such as Europe and

the United States, there typically is not a female bias for type 1 diabetes incidence or prevalence (Gale & Gillespie, 2001, Blohme, 1992, Ostrauskas, 2011).

The incidence and prevalence rates reported by Marshall et al. are much lower than rates reported in the United States and many other African countries (Marshall et al., 2015b). However, it is likely that geographical proximity to care is a barrier to diagnosing all diabetes cases (Marshall et al., 2015b).

In 2015, there were an estimated 138,000 cases of undiagnosed diabetes (largely type 2) in adults in Rwanda (Rwanda, 2015). Additionally, there were 194,300 total cases of diagnosed diabetes (largely type 2) among adults, ages 20-79, and 4,476 deaths in adults attributed to all types of diabetes in 2015 (Rwanda, 2015).

People with diabetes must manage the emotional aspects of the disease, including stigma, as well as the physical aspects. Stigma has been studied extensively in patients with a variety of diseases and conditions such as mental illnesses, HIV/AIDS, and obesity; however, stigma has not been studied as thoroughly in the context of type 1 diabetes. Stigma has been known to affect self-esteem, quality of life, and willingness to seek and adhere to treatment (Brown et al., 2014, Rusch et al., 2005, Puhl & Heuer, 2010). Stigma may also hinder efforts for prevention and disease management (Puhl & Heuer, 2010).

Diabetes-related stigma has been studied *qualitatively* within diverse cultural contexts, with observed negative associations on both physical and mental health (Hapunda et al., 2015, Jaacks et al., 2015, Balfe et al., 2013, Abdoli et al., 2013). Understanding perceived stigma associated with type 1 diabetes has the potential to improve psychological well-being and self-management. Additionally, reducing stigma may also help improve glycemic control as well as

reduce the risk of other serious diabetes-related complications (Balfe et al., 2013, Jaacks et al., 2015).

1.1 Type 1 Diabetes

Type 1 diabetes has a strong genetic component that can be traced to human leukocyte antigen (HLA) class II genes (Steck & Rewers, 2011, Wang et al., 2016, Bushcard, 2011, Nguyen, 2013, Singal & Blajchman, 1973). This class of genes accounts for about 40%-60% of the genetic risk for type 1 diabetes (Steck & Rewers, 2011, Wang et al., 2016). Other loci may also be involved; however, risk is much smaller than that traced to the HLA genes (Steck & Rewers, 2011). The pattern of inheritance of type 1 diabetes is not Mendelian (Steck & Rewers, 2011, Cordell & Todd, 1995). However, the genetic influence for type 1 diabetes is less strong than that for type 2 diabetes as seen by high concordance rates ranging from 60-90% among monozygotic twins (Medici et al., 1999, Kaprio et al., 1992) whereas concordance for type 1 diabetes ranges from 4-27% (Hyttinen et al., 2003, Kaprio et al., 1992).

Thus, research shows, it is a combination of genetics and environmental conditions that determines type 1 diabetes development (Wang et al., 2016, Steck & Rewers, 2011, Anaya et al., 2006, Cordell & Todd, 1995). Familial clustering is common with type 1 diabetes (Steck & Rewers, 2011, Anaya et al., 2006, Cordelll & Todd, 1995). In the United States, siblings of people with type 1 diabetes are at a 6% risk for development compared to a 0.4% risk of the general population (Steck & Rewers, 2011, Cordell & Todd, 1995, Thomson et al., 1988). Additionally, offspring with a father that has type 1 diabetes are at higher risk of disease

development (~12%) compared to offspring of a mother with type 1 diabetes (~6%) (Steck & Rewers, 2011).

Type 1 diabetes is an autoimmune disorder. It occurs when the immune system destroys beta cells in the pancreas (Diabetes, 2016, Global Report on Diabetes, 2016, What is Type 1 Diabetes, 2016, Type 1 Diabetes, 2013). As a result, the pancreas does not produce any insulin (Diabetes, 2016, What is Type 1 Diabetes, 2016, Type 1 Diabetes, 2013). Without insulin, sugar in the bloodstream cannot be transported into cells for energy (Diabetes, 2016, What is Type 1 Diabetes, 2016, Type 1 Diabetes, 2013).

Insulin therapy protects against dangerous diabetes-related complications such as diabetic ketoacidosis and is required in order for people to regulate the amount of sugar in their blood (Diabetes, 2016, What is Type 1 Diabetes, 2016, Type 1 Diabetes, 2013). However, individuals in developing countries, especially Africa, are dying due to lack of access to insulin (Beran et al., 2015, Beran & Yudkin, 2010). It is estimated that only one-third of people worldwide have access to proper medications, and in Sub-Saharan Africa life expectancy of a child is less than 1 year if they do not have access to insulin (Beran et al., 2015).

Chronic microvascular complications such as diabetic retinopathy, neuropathy and nephropathy, and macrovascular complications such as coronary artery disease, stroke and peripheral arterial disease, may occur with diabetes (Type 1 Diabetes, 2014, Fowler, 2008). The risk of microvascular complications can be reduced with proper insulin therapy (Viswanathan, 2005, Type 1 Diabetes, 2014, Ohkubu et al., 1995). If patients are able to control blood sugar, lipids and blood pressure, risk of microvascular and macrovascular complications and death decreases (Elliott et al., 2011, Viswanathan, 2005).

1.2 Diabetes Management

Maintaining normal blood glucose levels limits the risk of additional complications of type 1 and type 2 diabetes (Wild et al., 2007, Hypoglycemia 1997, Turner et al., 1998, Shamoon et al., 1993). With the maintenance of blood glucose levels through insulin treatment comes the risk of hypoglycemia (McCall, 2012, Wild et al., 2007, Hypoglycemia 1997). Glycemic management of diabetes is greatly limited by hypoglycemia (Wild et al., 2007, Hypoglycemia, 1997, Cryer, 1994). The Diabetes Control and Complications Trial reported that intensive insulin therapy (INT) is effective for controlling blood glucose levels and reducing the risk of microvascular complications (The DCCT Research Group, 1997). However, INT is also associated with an increased risk for hypoglycemia, which has its own negative effects (The DCCT Research Group, 1997).

Hypoglycemia is one of the most common complications associated with insulin treatment (Morales & Schneider, 2014, Graveling & Frier, 2009, Wild et al., 2007, Hypoglycemia, 1997). Symptoms may include shaking, sweating, mental confusion, negative mood, and nausea (Morales & Schneider, 2014, Graveling & Frier, 2009, Henderson et al., 2003, Wild et al., 2007). A severe case of hypoglycemia could result in injuries, motor vehicle accidents, or death (Wild et al., 2007).

This risk creates challenges for those with diabetes to retain normal glycated hemoglobin (HbA1c) levels throughout life (Wild et al., 2007, Hypoglycemia, 1997, Cryer, 1994). Clinicians use HbA1c as a marker to determine levels of glycemia over the course of a few weeks or months (Rewers et al., 2014). High HbA1c levels reflect poor control of diabetes and

are associated with a higher risk of diabetes-related complications (Guide to HbA1c, 2017, Rewers et al., 2014, The DCCT Research Group, 1993).

There are numerous barriers to diabetes management. From the patients' standpoint, research shows that psychological problems are a barrier to glycemic control (Lancaster et al., 2010, Anderson et al., 2010, Hassan et al., 2006, Lernmark et al., 1999, Lloyd et al., 1999). Patients with type 1 diabetes that experienced poor or declining glycemic control were more likely to report severe personal stressors in the month prior to measurement as compared to those whose glycemic control improved or remained adequate (Lloyd et al., 1999). Stigma may contribute to stressors that impact physical and psychological wellbeing, as stigma is a source of distress (Balfe et al., 2013). Stress, in turn, may impact a patient's ability to monitor glucose as often as needed, follow a strict diet, and adhere to a prescribed insulin regimen (Hapunda et al., 2015). Additionally, signs of depression have been linked to poor glycemic control (Anderson et al., 2010, Hassan et al., 2006, Lernmark et al., 1999).

In the United States and England, family conflict (Lancaster et al., 2010, Anderson et al., 2002, Swift et al., 2006), low socioeconomic status (Rewers et al., 2002, Swift et al., 2006,) and being a child with type 1 diabetes from a single-parent household (Rewers et al., 2002, Swift et al., 2006) have also been identified as barriers to achieving adequate glycemic control. Additionally, American adults with low health literacy, as well as children with parents with low health literacy, are also more likely to have poor glycemic control (Osborn et al., 2009, Janisse et al., 2010). Young adults ages 17-29 living in the United States have expressed that due to the unpredictability of their lifestyles, they find insulin treatment inconvenient (Lancaster et al., 2010).

Clinicians' attitudes towards and knowledge about diabetes may also be a barrier to glycemic control (Nam et al., 2011, Puder & Keller, 2003, Dietrich, 1996). Also, if clinicians have poor communication skills, there is a poorly designed healthcare system in place, or if providers and patients have differing perceptions about diabetes, diabetes self-management may also be negatively impacted (Nam et al., 2011, Puder & Keller, 2003, Dietrich, 1996).

Self-management and health beliefs may be affected by culture, language and health literacy (Nam et al., 2011). In developing nations, lack of access to insulin (Marshall et al., 2015 Type 1 Diabetes, 2014, Beran & Yudkin) and lack of financial resources are major barriers to glycemic control and diabetes management (Nam et al., 2011). Factors such as having a support system and co-morbidities may also affect a patient's ability to manage their diabetes adequately (Nam et al., 2011). Being able to properly identify barriers to diabetes management is necessary in order to improve quality of care and disease management (Nam et al., 2011).

1.3 Diabetes Resources in Rwanda

In 2015, the mean diabetes-related healthcare expenditure was $131.40 per person per year (Rwanda, 2015) and the gross national income per capita was $700 in Rwanda (GNI per capita, 2016). The community-based insurance structure, which is primarily a program called Mutuelles de Sante (Health System, 2014), covers 90% of primary care costs (Rwanda IDF). Services for prevention, diagnosis and treatment such as insulin, glibenclamide and metformin, are included. However, these services are not universally covered (Rwanda IDF). Diabetes management education is limited and services to prevent complications are not covered (Rwanda IDF).

Life for a Child

In 2015, the International Diabetes Federation's program, Life for a Child (LFAC), assisted over 18,000 youth with diabetes in 46 countries (The Programme, 2015). Established in 2000, this program provides basic supplies, care and education for those with type 1 diabetes. Insulin, syringes, clinical care, diabetes education, blood glucose monitoring equipment, technical support for health care workers, and HbA1c testing are provided (The Programme, 2015).

Diabetes care is often unavailable in Rwanda (Marshall et al., 2015b). LFAC has been working in Rwanda in order to provide specialized care to youth with insulin and other diabetes supplies (Marshall et al., 2015).

All participants must be Rwandan citizens, under the age of 26 years, and must need assistance managing their diabetes (Marshall et al., 2015b). Most youth and young adults with type 1 diabetes in Rwanda participate in the LFAC program in order to obtain care because there is a lack of alternative resources (Marshall et al., 2015b).

Rwanda Diabetes Association

The Rwanda Diabetes Association (RDA) is a non-governmental organization located in Kigali that opened in 1997 and became a member of the International Diabetes Federation in 2003 (Our Story, 2017). RDA's mission is to promote care, prevent future cases of diabetes and support people with diabetes and their families (Our Story, 2017).

Due to high prices and limited access to insulin, the majority of people with type 1 diabetes are referred to the RDA (Marshall et al., 2015). The RDA has expanded its services from Kigali to serve the majority of the country (Marshall et al., 2015b).

Vocational Center

Marjorie's Fund, a charity aimed to empower people with type 1 diabetes, partners with LFAC and RDA in order to run the Rwanda Diabetes Education Center (Rwanda Diabetes, 2016). This is a local education program that covers topics such as diabetes management, nutrition and vocational skills (Rwanda Diabetes, 2016).

Programs that offer support to individuals with diabetes exist in Rwanda; however, once patients age out of these programs, it is more difficult to manage the disease (Rwanda Diabetes, 2016). This six-month program aims to teach young adults to become independent with regard to disease management, including development of skills necessary to obtain continual diabetes-related supplies after they age out of diabetes support programs such as LFAC (Rwanda Diabetes, 2016).

1.4 Stigma

Sources and causes of stigma may vary from country to country, as it is a social construct (Hapunda et al., 2015, Jaacks et al., 2015, Mahajan et al., 2008). Stigma may include labeling, stereotyping, judging, placing blame on the individual, and rejecting an individual or a group (Abdoli et al., 2013, Link & Phelan, 2001, Puhl & Heuer, 2010, Puhl & Brownell, 2003, Crandall, 1994, McHenry et al., 2016, Valdiserri et al., 2002). It may result in discrimination from the general public, institutions, and healthcare professionals (Rusch et al., 2005, Lauber et al., 2004, Matschinger & Angermeyer, 2004, Corrigan & Watson, 2003, Gray, 2002) and it can be associated with communicable or non-communicable diseases (Abdoli et al., 2013, Phelan & Link, 2001).

Stigma may prevent individuals from seeking preventative care, screening, and follow-up care, especially if they have experienced judgmental attitudes in the past (Puhl & Heuer, 2010, Bayer, 2008, McHenry et al., 2016, Brown et al., 2014, Mahajan et al., 2008, Rusch et al., 2005, Corrigan, 2004, Schulze & Angermeyer, 2003). This has been reported consistently throughout the literature regarding HIV/AIDS, mental illness, and obesity (Puhl & Heuer, 2010, Bayer, 2008, McHenry et al., 2016, Brown et al., 2014, Mahajan et al., 2008, Rusch et al., 2005, Corrigan, 2004, Schulze & Angermeyer, 2003). Stigma may also contribute to someone's willingness to adhere to treatment (Rusch et al., 2005, Corrigan, 2004, Schulze & Angermeyer, 2003). Individuals are more likely to get tested if they perceive that the healthcare center and workers are nonthreatening, nonjudgmental, and will cater to their needs with care (Valdiserri et al., 2002).

Stigma may produce stress indirectly (Miller & Major, 2000). This is partly due to negative attitudes surrounding these conditions, which is associated with low self-esteem (Werner et al., 2008, Rusch et al., 2005, Corrigan, 2004, Puhl & Heuer, 2010, Miller & Major, 2000). Additionally, people who feel stigmatized often have an increased frequency of self-threats, including suicide and self-injurious behaviors, and have less access to resources such as housing, education, and employment (Miller & Major, 2000).

1.5 Diabetes-Related Stigma

Diabetes-related stigma has been qualitatively studied throughout the world in countries such as Tanzania, Zambia, South Africa, Australia, Iran and China, to investigate the experiences of individuals living with this condition within specific cultural contexts. Similar to

stigma related to other diseases and conditions, diabetes-related stigma could have a major negative impact on psychological and physical well-being (Browne et al., 2014, Abdoli et al., 2013, Balfe et al., 2013).

As stigma is a social construct that varies around the world, each country is unique when examining diabetes-related stigma (Hapunda et al., 2015). Qualitative analyses of type 1 diabetes-related stigma throughout the world have shown different sources of stigma, but similar effects of diabetes-related stigma.

Thus, sources of diabetes-related stigma differ between such diverse countries as Zambia, China, Iran, Ireland, and Australia (Hapunda et al., 2015, Jaacks et al., 2015, Abdoli et al., 2013, Balfe et a., 2013, Browne et al., 2014). In Zambia, stigma arises from the belief that type 1 diabetes is a communicable disease (Hapunda et al., 2015). In China, type 1 diabetes is a rare disease, so people with this condition are seen as monsters and are blamed for their disease (Jaacks et al., 2015). Type 1 diabetes-related stigma in Iran and Ireland may stem from negative labeling that individuals with diabetes are miserable people and unable to live a normal life (Abdoli et al., 2013, Balfe et al., 2013). Finally, in Australia, people with type 1 diabetes are often mistaken as having type 2 diabetes or are misidentified as injection drug users (Browne et al., 2014); therefore, people with type 1 diabetes in this setting must confront the stigmatizing beliefs that surround both that of type 2 diabetes and injection drug use (Browne et al., 2014). People with type 1 diabetes in Australia are often blamed for management difficulties (Browne et al., 2014). Both sources and consequences of stigma in each of these countries contribute to individuals often choosing to hide their condition

(Hapunda et al., 2015, Jaacks et al., 2015, Abdoli et al., 2013, Balfe et a., 2013, Browne et al., 2014).

Studies in Zambia, China, Iran, Ireland, and Australia have shown that diabetes stigma is a barrier to relationships (Hapunda et al., 2015, Jaacks et al., 2015, Abdoli et al., 2013, Balfe et a., 2013, Browne et al., 2014). Participants in each of these studies expressed concerns in finding a spouse and being unfit for marriage due to the stigma that surrounds type 1 diabetes (Hapunda et al., 2015, Jaacks et al., 2015, Abdoli et al., 2013, Balfe et a., 2013, Browne et al., 2014). Additionally, participants in Zambia, Iran, and Ireland all expressed concerns in being seen as unfit to reproduce (Hapunda et al., 2015, Abdoli et al., 2013, Balfe et al., 2013). Further, participants in Iran reported that diabetes-related stigma negatively impacted relationships and may have contributed to divorce and/or sexual issues between partners (Abdoli et al., 2013).

Type 1 diabetes-related stigma also contributes to exclusion from activities and avoidance of treatment options that may highlight the disease, such as wearing an insulin pump or attending a support group (Balfe et al., 2013). Reports from Zambia and Australia showed that adolescents often felt excluded from school and social activities because of their disease (Hapunda et al., 2015, Browne et al., 2014). Additionally, people in China reported that they avoided using health insurance to purchase necessary equipment so that their name would not be associated with diabetes (Jaacks et al., 2015).

People with type 1 diabetes in China not only face stigmatizing beliefs from the public, but must also overcome institutional stigmatizing policies that restrict college admission and government employment (Jaacks et al., 2015). This further perpetuates the need for people

with type 1 diabetes to hide their disease status. To summarize, manifestations of diabetes-related stigma differ throughout the globe, yet the impact of stigma shows a common impact on everyday life (Hapunda et al., 2015, Jaacks et al., 2015, Abdoli et al., 2013, Balfe et a., 2013, Browne et al., 2014).

1.6 Measures of Stigma

Type 1 diabetes-related stigma has been studied extensively through qualitative, in-depth, semi-structured interviews (Hapunda et al., 2015, Jaacks et al., 2015, Balfe et al., 2013, Abdoli et al., 2013). These interviews allow researchers to gain deeper insight into individuals' experiences with type 1 diabetes. A diabetes-specific stigma scale does not exist; therefore, quantitative data is not yet available.

Stigma can be examined in numerous ways. Many diseases and conditions have specific stigma scales that allow researchers to quantify the amount of stigma in a population. For example, the Berger HIV Stigma Scale (Berger et al., 2001) and the Van Rie HIV/AIDS-Related Stigma Scale (Kipp et al., 2015) are used to assess stigma in people with HIV/AIDS. Stigma questionnaires related to mental health include the Opening Minds Scale for Health Providers (Kassam et al., 2012) and The Stigma Scale (King et al., 2007).

Currently, there are gaps in the literature regarding type 1 diabetes-related stigma. Since past research has examined this issue qualitatively, diabetes stigma has not been quantified and compared amongst different groups. Additionally, there has not been any type 1 diabetes-related stigma research done in Rwanda. In order to address these gaps, we have conducted interviews with youth and young adults with type 1 diabetes in Rwanda using a

structured questionnaire. This issue is of high public health significance because research has found that stigma may prevent people from seeking care for their conditions as well as preventative care (McHenry et al., 2016, Brown et al., 2014, Mahajan et al., 2008). Additionally, stigma may affect treatment adherence (Rusch et al., 2005, Corrigan, 2004, Schulze & Angermeyer, 2003), negatively impact psychological and physical well-being, and limit work and educational opportunities (Browne et al., 2014, Abdoli et al., 2013, Balfe et al., 2013, Werner et al., 2008, Rusch et al., 2005, Corrigan, 2004, Jaacks et al., 2015). Understanding correlates of stigma may allow for targeted interventions that aim to minimize perceived stigma, thus, improving psychological well-being and self-management of type 1 diabetes.

2.0 Objective

The aim of our study was to examine the correlates of perceived stigma in the context of type 1 diabetes among youth and young adults in Rwanda. We hypothesized that HbA1c levels and perceived stigma would be positively correlated. Additionally, we hypothesized that participants in the LFAC program with poor glycemic control (HbA1c ≥ 7%) (The A1c Test, 2014) would exhibit higher levels of perceived stigma as compared to those with adequate glycemic control (HbA1c < 7%). We further hypothesized that stigma would differ by age, duration of diabetes would be negatively associated with perceived stigma, and females would perceive more stigma than males. Finally, we hypothesized that those who attended the vocational center status would perceive less stigma than those who did not attend the center.

3.0 Methods

3.1 Participants

The University of Pittsburgh Institutional Review Board granted ethics approval for an ongoing survey of youth with diabetes in Rwanda, of which this study is a part. Nine hospitals were included in the sample; 5 in the Western Province, 3 in the Southern Province, and 1 in the Eastern Province. Hospitals with a sizeable pool of former vocational center attendees were targeted for recruitment. Public radio was used to announce the quarterly visit date when RDA staff would be present. Additionally, nurses called patients on cell phones to advertise recruitment.

All potential participants that were approached provided written informed consent to University of Pittsburgh study personnel. Participants (N=54, 57% female) comprised both current and former LFAC participants ages 15-32. Study personnel administered the adapted Berger HIV Stigma Scale (described below) along with other survey items related to quality of life and diabetes care (Berger et al., 2001). HbA1c information was measured using the DCA 2000 Vantage® Analyzer at the time of the quarterly hospital visit. Information on age, duration of diabetes, and sex were obtained through previous LFAC visits.

3.2 Adapted Berger HIV Stigma Scale

The Berger HIV Stigma Scale is a 40-item questionnaire used to assess level of perceived stigma in patients with HIV (Berger et al., 2001), and has been validated cross-culturally (Berger et al., 2001). For the current study, the Stigma Scale was adapted to fit cultural, as well as a

diabetes-related context. Statements were left out if there was not a proper translation, and all statements were changed to inquire about diabetes rather than HIV.

The adapted version contained 25 questions, was translated into the official language of Rwanda (Kinyarwanda), and was administered verbally by study personnel (Appendix). The interview took about 20 minutes to complete, and contained questions such as "I work hard to keep my diabetes a secret" and "People with diabetes are treated as outcasts". Participants answered on a Likert Scale (strongly disagree, disagree, agree or strongly agree).

Each possible answer corresponds with a point value, ranging from 1 (strongly disagree) to 4 (strongly agree)(Berger et al., 2001). If a participant selected an answer between two options (i.e. between agree and strongly agree), the midpoint was used (Berger et al., 2001). Two items, 8 and 16 (Appendix), were reversed scored. Raw values for each question were added in order to obtain the overall score. The range of possible scores was 25-100. Higher scores are indicative of higher levels of perceived stigma (Berger et al., 2001).

3.3 Analysis

Perceived stigma scores were summarized using medians and interquartile ranges. Spearman's correlation coefficients were used to assess the association between stigma and HbA1c level, age, and duration of diabetes. We used Wilcoxon rank sum tests to compare stigma scores by glycemic control status (HbA1c <7% and HbA1c ≥ 7%) (The A1c Test, 2014), sex, and vocational center attendance. An alpha level of 0.05 was used to calculate p-values. Data analysis was conducted using SAS (version 9.4, SAS Institute Inc., Cary, NC, USA).

4.0 Results

Among participants (N=54, 57% female), the median age was 26 (IQR: 23-28) and 24 were current participants in the LFAC program (Table 1). Stigma scores ranged from 49-83, with a median value of 64 (IQR: 55-67) (Table 3).

A subset of the study population (N=28, 64% female) had current HbA1c measurements available for analysis (Table 2). Within this subset, perceived stigma scores ranged from 49-83, with a median value of 66 (IQR: 56-69). Adequate glycemic control (HbA1c <7%) was exhibited in 11 (39%) participants and 17 (61%) exhibited poor glycemic control (HbA1c≥7%) (Table 3).

There was a weak positive correlation between perceived stigma and HbA1c (Correlation and Regression, 2017) (r_s=0.31, 95% CI= -0.07-0.61, p=0.11). Perceived stigma differed minimally between those with adequate glycemic control (median= 64, IQR: 50-71) and those with poor glycemic control (median=66, IQR: 62-69) (p=0.25) (Table 3).

In our full sample, perceived stigma and age had a weak, negative association (r_s=-0.21, 95% CI= -0.45-0.06, p=0.14) (Figure 2), as did perceived stigma and diabetes duration (r_s=-0.23, 95% CI= -0.47-0.04, p=0.1) (Figure 3).

As predicted, median stigma scores were higher in females (median=66, IQR: 58-69) than males (median=56, IQR: 53-66) (p=0.01) (Table 3). This difference was statistically significant (p=0.01).

We also saw a difference in score distributions by vocational center attendance. People who had attended the vocational center had significantly higher perceived stigma scores (median=66, IQR: 62-69) as compared to those who had not attended the vocational center (median=54, IQR: 52-62) (p<0.01) (Table 3). Among the 38 vocational center attendees, of

whom 61% were female, perceived stigma differed minimally between males (median=63, IQR: 56-67) and females (median=66, IQR: 64-70) (p=0.1).

Table 1. Selected characteristics of study participants, (a) overall; (b) by vocational center attendance; and (b) by Life for a Child (LFAC) participation status.

	(a)	(b) Vocational Center Attendee?		(c) LFAC Status	
Characteristic	**All** (N=54)	**No** (N=16)	**Yes** (N=38)	**Current** (N=24)	**Former** (N=30)
Female, N (%)	31 (57%)	8 (50%)	23 (61%)	16 (67%)	30 (100%)
Age, years					
Median (IQR)	26 (23-28)	28 (27-30)	24.5 (22-27)*	23 (20-24)	28 (27-29)**
(Range)	(15-32)	(25-32)	(15-32)	(15-25)	(26-32)
Diabetes Duration, years					
Median (IQR)	7 (6-9)	9 (6-13)	7 (5-9)	7 (4-9)	7.5 (6-9)
(Range)	(3-20)	(4-18)	(3-20)	(3-20)	(4-18)
Vocational Center Attendee, N (%)	38 (70%)	-	-	22 (92%)	16 (53%)*
Current LFAC Participant, N (%)	23 (43%)	1 (6%)	22 (58%)*	-	-

**p<0.005*
***p<0.0001*

Table 2. Selected characteristics of study participants with available HbA1c, (a) overall, (b) by vocational center attendance, and (c) by Life for a Child (LFAC) participation status.

Characteristic	(a) All (N=28)	(b) Vocational Center Attendee? No (N=3)	(b) Vocational Center Attendee? Yes (N=25)	(c) LFAC Status Current (N=20)	(c) LFAC Status Former (N=8)
Female, N (%)	18 (64%)	1 (33%)	17 (68%)	13 (65%)	5 (63%)
Age, years					
Median (IQR)	24 (22-26)	25 (25-26)	24 (22-25)	23 (20.5-24)	26.5 (26-28)*
(Range)	(15-29)	(25-26)	(15-29)	(15-25)	(26-29)
Diabetes Duration, years					
Median (IQR)	7 (5-9.5)	13 (6-15)	7 (5-9)	7 (4-9.5)	7 (5.5-11)
(Range)	(3-20)	(6-15)	(3-20)	(3-20)	(5-16)
Vocational Center Attendee, N (%)	25 (89%)	-	-	19 (95%)	6 (75%)
Current LFAC Participant, N (%)	20 (71%)	1 (33%)	19 (76%)	-	-
HbA1c					
Median (IQR)	7.6 (6.25-9.6)	8.6 (7.7-8.8)	7.3 (6.2-10.4)	7.15 (6.15-9.9)	8.25 (7.1-9.6)
(Range)	(4.0-14.1)	(7.7-8.8)	(4.0-14.1)	(4.0-14.1)	(6.2-11.6)
Glycemic Control					
Adequate (HbA1c <7%)	11 (39%)	0 (0%)	11 (44%)	9 (45%)	2 (25%)
Poor (HbA1c ≥ 7%)	17 (61%)	3 (100%)	14 (56%)	11 (55%)	6 (75%)

**p<0.0001*

Table 3. Perceived stigma score distribution of all participants and participants with HbA1c measurements (a) overall, (b) by vocational center attendance, (c) by sex, and (d) by glycemic control.

	(a) All	(b) Vocational Center Attendee? No	(b) Vocational Center Attendee? Yes	(c) Sex Male	(c) Sex Female	(d) Glycemic Control Yes	(d) Glycemic Control No
All Participants, N	54	16	38	27	31	-	-
Stigma,							
Median (IQR)	64 (55-67)	54.5 (52-62)	66 (62-69)	56 (53-66)	66 (58-69)	-	-
(Range)	(49-83)	(51-69)	(49-83)	(50-83)	(49-74)		
p-value		<0.01		0.01			
Subset of Participants with HbA1c, N	28	3	25	10	18	11	17
Stigma,							
Median (IQR)	66 (56-69)	52 (51-56)	66 (56-67)	63 (56-67)	66 (62-70)	64 (50-71)	66 (62-69)
(Range)	(49-83)	(51-56)	(49-83)	(50-83)	(49-74)	(49-74)	(51-83)
p-value		0.053		0.3		0.25	

Table 4. Correlations between perceived stigma, HbA1c, age and diabetes duration.

	Perceived stigma	HbA1c	Age	Duration
Perceived Stigma	1			
HbA1c	0.31	1		
Age	-0.21	0.00	1	
Duration	-0.23	-0.11	0.26	1

**Correlations did not have significant p-values*

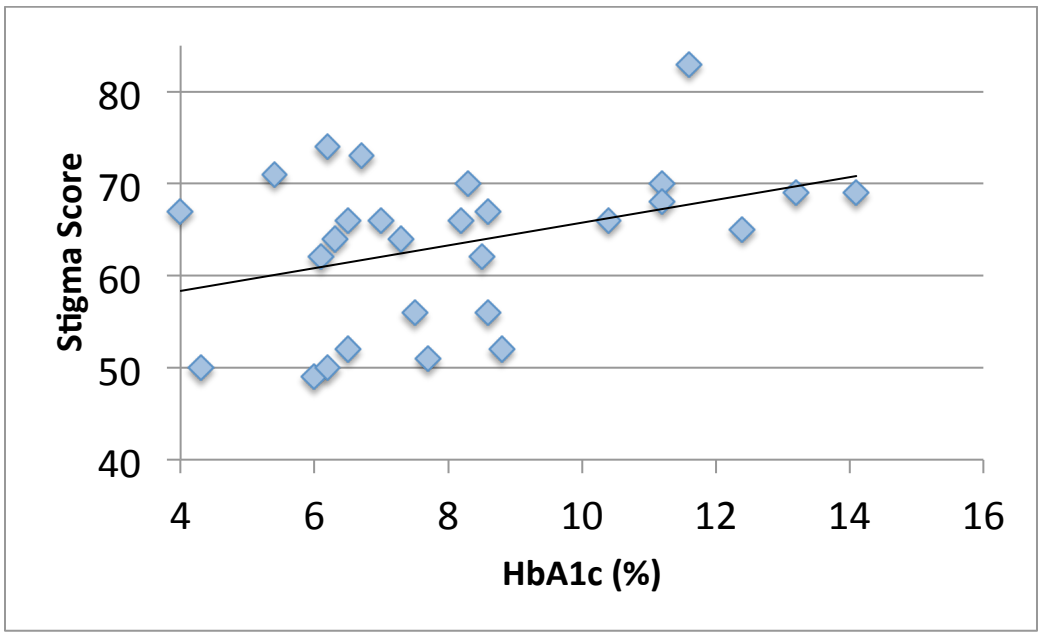

Figure 1. Perceived stigma and HbA1c levels have a positive association (r_s=0.31, 95% CI= -0.07-0.61, p=0.11).

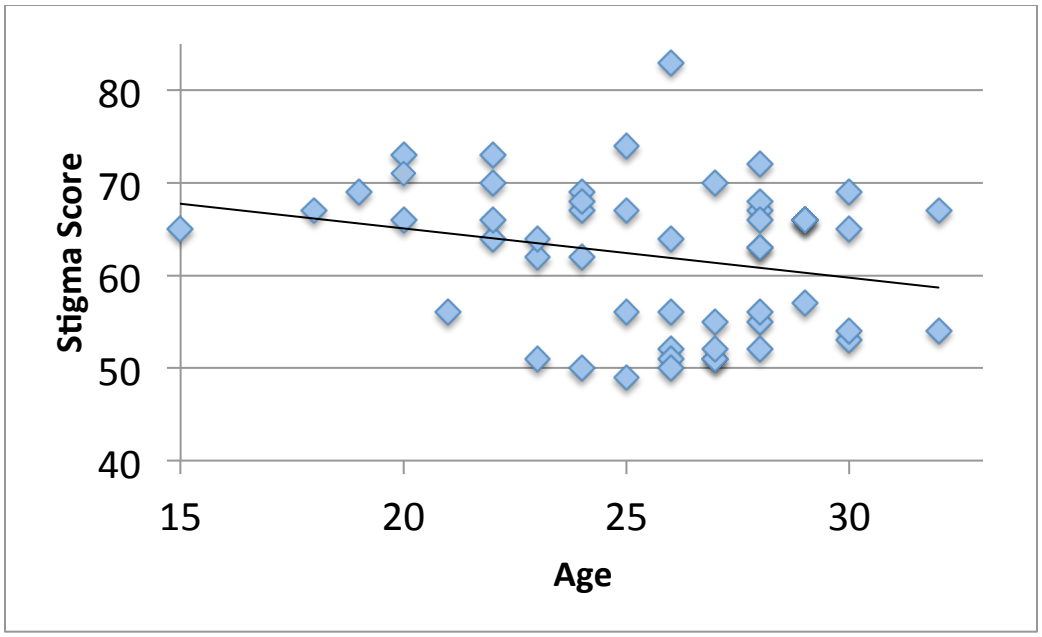

Figure 2. Perceived stigma and age have a weak, negative association (r_s=-0.21, 95% CI= -0.45-0.06, p=0.14).

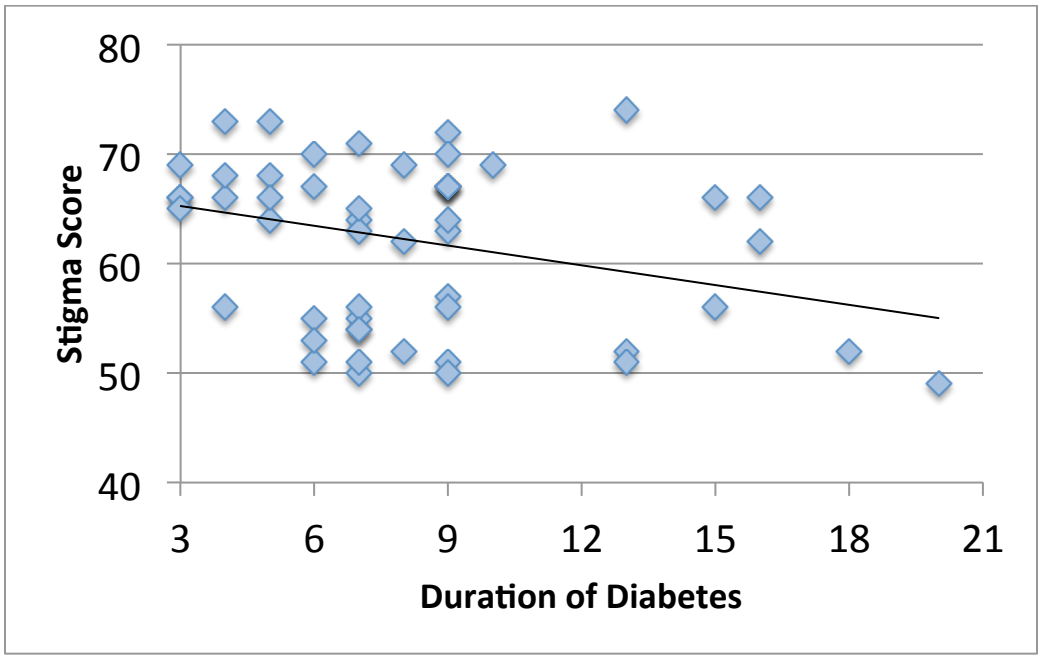

Figure 3. Perceived stigma and duration of diabetes have a weak, negative association (r_s=-0.23, 95% CI= -0.47-0.04, p=0.1)

6.0 Discussion

The aim of this study was to examine the effects of glycemic control, age, duration of type 1 diabetes, sex, and vocational center attendance on perceived stigma due to type 1 diabetes. We found that HbA1c level was weakly, but not significantly, correlated with perceived stigma. Additionally, perceived stigma was not significantly higher in those with poor glycemic control compared to those with adequate control. Our sample size of participants with HbA1c measurements was small and therefore lacked power. Based on a post hoc power analysis with Pearson correlation estimates, our study would have needed a sample size of 63 in order to have 80% power to observe a statistically significant correlation of r_s=0.31. With our sample size of 28, we had 80% power to detect a minimum correlation of r_s=0.46. This preliminary data shows a potentially meaningful correlation. Future research with a larger sample size would be beneficial in order to have more power.

Age and duration of diabetes both had a weak negative correlations with stigma, and were not statistically significant. As predicted, perceived stigma differed between males and females as well as between those who attended the vocational center and those who did not.

We predicted that higher HbA1c levels and poor glycemic control would be associated with higher levels of perceived stigma. Though not significant, our results support this hypothesis. Previous research found that stigma is a source of distress for people with diabetes (Balfe et al., 2013). Additionally, it has been shown in patients with type 1 and type 2 diabetes that a higher level of distress is significantly associated with higher HbA1c levels (Lloyd et al., 1999, Fisher, Glasgow & Strycker, 2010).

A study in England, with a sample of 55 adults aged 16 years and older with type 1 diabetes, found that participants whose glycemic control remained poor or decreased over time were significantly more likely to report severe personal stressors in the month leading up to HbA1c measurement as compared to those whose glycemic control either remained adequate or improved (Lloyd et al., 1999). In addition, a sample of 463 adults with type 2 diabetes showed that 51.3% scored at or above the threshold on the Diabetes Distress Scale (DDS) indicating significant diabetes distress (Fisher, Glasgow & Strycker, 2010). Similarly to Lloyd et al., this study found that diabetes distress was significantly, positively associated with HbA1c (Fisher, Glasgow & Strycker, 2010). Though we could not confirm these findings statistically, our own observation of a modest, but positive association between HbA1c and perceived stigma were in line with this previous research. At about 9%, HbA1c and perceived stigma scores seem to be more positively associated, potentially suggesting a threshold value.

Previous type 1 diabetes-related stigma research has studied individuals ranging in age from 12 to 36 years old (Abdoli et al., 2013, Hapunda et al., 2015). However, since past research was qualitative, the age-stigma association has not been studied in this population. However, age has been examined in relation to stigma – with varying results - in studies focused on different conditions, including depression, HIV/AIDS, and obesity.

One study regarding the stigma of depression examined three age groups (12-25, 26-55, and 56-101). This research found that participants aged 12-15 experienced more stigmatizing events as compared to older age groups (Stuart et al., 2014), while research studying HIV and obesity show that older adults experienced more stigma (Emlet, 2006, Lee et al., 2002, Puhl & Brownell, 2006). These studies were all cross-sectional in nature, and therefore cannot imply

causation. Similar to our study, they each were prone to sampling bias due to the intentional choice of population and the willingness of people who chose to participate. Additionally, these studies took place in different geographic regions than did the current study. Therefore, they cannot be generalized to the current context in Rwanda. However, the weak, negative association between age and perceived stigma that we found is in line with the previous findings from the Pacific Northwest (ages 20-39 and 50+), Wisconsin and New York City (ages 21-60) in adults with HIV, as well as the national sample studying obesity (ages 18-89) (Emlet, 2006, Lee et al., 2002, Puhl & Brownell, 2006). It is possible that the age range of our study sample did not have enough variability to detect a larger association.

Previous research in the United States surrounding HIV and internalized stigma found that participants with high levels of internalized stigma were more recently diagnosed with HIV, suggesting that, over time, people gain experience coping with their disease (Lee et al., 2002). However, a study in patients with schizophrenia in Greece found the opposite association. Stigma and duration of illness were positively associated, with participants that were ill for up to 10 years reporting less stigma than those who were ill 11-20 years and more than 21 years (Karidi et al., 2010). The weak, negative correlation between duration of diabetes and stigma that we found in our study is similar to the findings in people with HIV where participants with shorter disease duration perceive more stigma.

Numerous qualitative studies have shown that women with type 1 diabetes often feel stigmatized as not being fit for marriage and attempt to hide their disease (Hapunda et al., 2015, Abdoli et al., 2013, Browne et al., 2014). Additionally, people without diabetes may think

that women with diabetes are more likely to have a difficult pregnancy (Abdoli et al., 2013). Our results add to the evidence that females perceive higher levels of stigma than males.

The vocational center in Rwanda typically accepts 40 people per year to stay at the facility. Individuals selected for the program are usually those who need the most assistance with diabetes management and are struggling the most financially. Our research found that people who attended the vocational center in the past perceived significantly higher levels of stigma than those who have never attended, which may reflect selection bias if those more needing of assistance are more likely to perceive or attract stigma. Although over half of the center attendees sampled were females (N=23, 61%), we did not find a statistically significant difference of perceived stigma between males and females who attended the center, suggesting that this finding is an effect of the vocational center and not sex. A further explanation may be that although the purpose of the vocational center is to assist people with type 1 diabetes management, center attendees may have felt singled out or that others noticed them attending the vocational center, thus leading to increased perceived stigma. Also, study participants who attended the vocational center may be more willing to talk about their experiences related to stigma. Since center attendees may be worse off financially compared to non-attendees, it is possible that there may be an association between income and perceived stigma.

The current study has some limitations. The modified version of the questionnaire we used was not validated or used to examine perceived stigma in type 1 diabetes before. While the original Berger HIV Stigma Scale is validated cross-culturally, we had to adapt it in order to fit the context of diabetes in Rwanda. Additionally, there is a chance of selection bias. Our

participants were recruited using public radio and cell phone calls. Therefore, our sample was limited to those with access to technology and transportation to the hospital. Additionally, only 28 participants had current HbA1c measurements.

This was the first study that we know of to quantitatively examine stigma among people with type 1 diabetes. We were able to capture participants that are currently in the LFAC program as well as participants that have aged out. We also sampled from multiple regions of the country.

In the future, a larger sample size and more complete HbA1c data would be beneficial in determining its association with stigma. A larger sample size would provide more power to see any differences between groups of participants. Additionally, a validated questionnaire is needed in order to more accurately capture which groups of people are experiencing increased perceived stigma, as well as the prevalence of stigma**.** A study is currently taking place in Canada to develop a survey that will estimate the prevalence and scope of stigma in adolescents and young adults (Brazeau et al., 2016). A pilot study has shown good test-retest reproducibility, which may make it a potential option for future studies looking to quantify perceived stigma (Brazeau et al. 2016).

In the future, it would be beneficial to explore why the vocational center may impact perceived stigma. Studying variables such as education level, income and geography (urban versus rural) could potentially offer some insight on our findings.

Understanding correlates of perceived stigma has high public health significance. Research has shown that perceived stigma impacts psychological well-being and diabetes management (Balfe et al., 2013, Sturt et al., 2015). Our study aimed to explore potential

correlates of perceived stigma in order to find vulnerable populations that may be targeted for future interventions aiming to reduce stigma. We found that HbA1c level had a slight positive association with perceived stigma; however this association was not statistically significant. Age and duration of diabetes both had weak, negative associations with perceived stigma; however, these results were also not statistically significant. Females experienced more perceived stigma than males as well as vocational center attendees compared to non-attendees. Future interventions aimed at these populations could potentially improve mental health and self-management of type 1 diabetes.

Appendix: Adapted Berger HIV Stigma Scale

For each item, circle your answer: Strongly disagree (SD), disagree (D), agree (A) or strongly agree (SA).

1. In many areas of my life, no one knows that I have diabetes	SD	D	A	SA
2. I feel guilty because I have diabetes	SD	D	A	SA
3. People's attitudes about diabetes make me feel worse about myself	SD	D	A	SA
4. Telling someone I have diabetes is risky	SD	D	A	SA
5. People with diabetes lose their jobs when their employers find out	SD	D	A	SA
6. I work hard to keep my diabetes a secret	SD	D	A	SA
7. I feel I am not as good a person as others because I have diabetes	SD	D	A	SA
8. I never feel ashamed of having diabetes	SD	D	A	SA
9. People with diabetes are treated like outcasts	SD	D	A	SA
10. It is easier to avoid new friendships than worry about telling someone that I have diabetes	SD	D	A	SA
11. Since learning I have diabetes, I feel set apart and isolated from the rest of the world	SD	D	A	SA
12. Most people with diabetes are rejected when others find out	SD	D	A	SA
13. I am very careful who I tell that I have diabetes	SD	D	A	SA
14. Some people who know I have diabetes have grown more distant	SD	D	A	SA
15. Since learning I have diabetes, I worry about people discriminating against me	SD	D	A	SA

16. I never feel the need to hide the fact that I have diabetes	SD	D	A	SA
17. I have been hurt by how people reacted to learning I have diabetes	SD	D	A	SA
18. I worry that people who know I have diabetes will tell others	SD	D	A	SA
19. I regret having told some people that I have diabetes	SD	D	A	SA
20. As a rule, telling others that I have diabetes has been a mistake	SD	D	A	SA
21. People I care about stopped calling after learning I have diabetes	SD	D	A	SA
22. Some people act as though it's my fault I have diabetes	SD	D	A	SA
23. I have stopped socializing with some people because of their reactions to my having diabetes	SD	D	A	SA
24. I have lost friends by telling them I have diabetes	SD	D	A	SA
25. I have told people close to me to keep the fact that I have diabetes a secret	SD	D	A	SA

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